

**Division Circular 38  
(N/A)**

**DEPARTMENT OF HUMAN SERVICES  
DIVISION OF DEVELOPMENTAL DISABILITIES**

Effective Date: March 15, 2000

Date Issued: March 1, 2000

Rescinds Division Circular #38, "Decision Making for the Terminally Ill" issued May 1, 1997.

I. **TITLE: Advance Directives and Decision Making for the Terminally Ill**

II. **PURPOSE:** To describe the policies and procedures regarding the applicability of Advance Directives to persons receiving services, Do Not Resuscitate (DNR) orders, withholding or withdrawing life sustaining treatment, and the procedure for declarations of death by staff physicians in developmental centers.

III. **SCOPE:** Provisions of this circular apply to all persons receiving services from the Division of Developmental Disabilities.

IV. **POLICIES:**

The requirements of this circular conform with the New Jersey Advance Directives for Health Care Act, N.J.S.A. 26:2H-53 et seq., the Federal Patient Self Determination Act, 42 USC 1395, and the Department of Human Services Rule at N.J.A.C.10:8.

An adult individual having capacity to make health care decisions can issue (execute) an Advance Directive including a DNR order in accordance with the Department of Human Services Rule at N.J.A.C.10:8.

An individual lacking capacity to make health care decisions or his/her guardian cannot issue (execute) an Advance Directive.

In accordance with the guidelines issued by the Board of Medical Examiners, the attending physician shall exercise the responsibility of determining whether a terminally ill patient has the capacity to make medical care and treatment decisions.

Do Not Resuscitate Orders are in the same category as Life Sustaining Medical Treatment.

DNR orders may be issued in accordance with the provisions described in this circular.

With respect to DNR orders and withholding or withdrawing Life Sustaining Medical Treatment for a patient being cared for in a community hospital, the policies, procedures and practices of the facility shall apply.

## V. **STANDARDS:**

- A. Definitions - For the purpose of this circular, the following terms shall have the meanings defined herein:

“Advance Directive” - means a written document executed in accordance with the requirements of the NJ Advance Directive for Health Care Act. It is a written instruction stating the person's general treatment philosophy and objectives, and/or the person's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life sustaining treatment.

“Capacity” - means an individual's ability to make health care and medical treatment decisions on his or her own behalf.

“Do Not Resuscitate (DNR)” - means a physician's written order not to attempt cardiopulmonary resuscitation in the event the person suffers cardiac or respiratory arrest.

“Emergency Care” - means immediate treatment provided to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

“Ethics Committee” - means a multi-disciplinary standing committee of the developmental center or community hospital which meets to review determinations to withhold or withdraw a patient's life-sustaining treatment as needed.

“Health Care Facility” – means a hospital, a residential health care facility or nursing home, a developmental center, or a private residential facility licensed under N.J.A.C. 10:47. Community residences licensed under N.J.A.C. 10:44A or 10:44B are not health care facilities.

“Hospice” – means a program of care for patients who have life-limiting illnesses, which is designed to allow these individuals to live as normal, comfortable, and full a life as possible until death. Hospice programs are approved and regulated by the Department of Health

“Immediate Family” - means spouse, children, parents, siblings whose addresses or other contact information are included in the client record. Immediate family may also include persons less closely related to the individual by blood or marriage, but who have been interested and involved with the individual's welfare.

“Life Sustaining Medical Treatment (LSMT)” - means the use of any medical device or procedure, artificially provided fluids and nutrition, drugs, surgery, or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function and thereby increase the expected life span of the person.

“New Jersey Protection and Advocacy, Inc. (P&A)” – means the organization designated by New Jersey Governor Christine Todd Whitman, in her September 27, 1994 letter to Commission of the United States Department of Health and Human Services, to be the agency to implement, on behalf of the State of New Jersey, the Protection and Advocacy System established under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§6041-6043.

“Permanently Unconscious” - means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes a persistent vegetative state or irreversible coma.

“Supportive Care Plan” - means a plan of care to be developed by the health care facility for each person for whom a DNR order is proposed. The plan is individualized to meet the person's needs and shall consider fluid/intravenous therapies, nutrition, symptom management/medication, invasive diagnostic and therapeutic procedures including but not limited to mechanical ventilation, kidney dialysis, pulmonary, arterial or venous catheters, transfusions, laboratory, x-ray and other tests.

“Terminally Ill Patient” – means an individual under medical care for whom the prognosis of the attending physician and at least one other physician asserts there is no hope of remission and cure.

- B. Unless the individual has been adjudicated as lacking capacity to make medical treatment decisions, a copy of the document “Your Right to Make Decisions in New Jersey” issued by the NJ Department of Health shall be provided to each person upon admission to a developmental center as well as to persons presently placed.
- C. The developmental center shall not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive.
- D. Any transfer from the developmental center shall include a copy of the advance directive.
- E. The developmental center shall educate staff, persons served and their families about issues surrounding advance directives.
- F. An advance directive does not imply that any other care or treatment may be withheld or withdrawn.

- G. In all cases, measures shall be taken to provide the person with maximum comfort and freedom from pain.

## VI. **PROCEDURES:**

### A. Advance Directives.

1. Health care staff at developmental centers shall determine if an Advance Directive exists at the time of admission.
2. Advance Directives shall be noted in the client record by the physician. The physician shall also note if the person is considered to have the capacity to issue (execute) an Advance Directive.
3. An Advance Directive shall be made in writing and the signature shall either be notarized or done in the presence of competent adults who attest as witnesses that the person is of sound mind and free of duress or undue influence. A copy of the Advance directive shall be placed in the client record.
4. A woman may indicate what measures to take if she is pregnant.
5. An Advance Directive may be revoked at any time either orally or in writing.
6. If an Advance Directive is issued, the requirements of N.J.A.C. 10:8.2 shall be followed.

### B. Determination of Patient's Capacity Regarding Do Not Resuscitate Orders or the Withholding or Withdrawing of Life Sustaining Treatment For Terminally Ill Patients

1. It is the attending physician's role to recommend a course of treatment for a terminally ill patient, including a Do Not Resuscitate Order (DNR) and/or the withholding or withdrawing of Life Sustaining Medical Treatment (LSMT).
2. If the attending physician recommends a DNR order or the withdrawal or withholding of LSMT, the physician must determine whether the individual has the capacity to make medical treatment decisions. The attending physician's recommendation to withhold or withdraw LSMT should be reviewed by the facility's Ethics Committee.
3. The attending physician may rely on information supplied by the Division of Developmental Disabilities or the Bureau of Guardianship Services to determine whether the terminally ill patient has the capacity to make medical determination. The

attending physician shall be the final arbiter of this determination.

4. To the extent possible, D.D.D. staff shall provide to the attending physician any information or records pertinent to the issue of whether a terminally ill patient may or may not have the capacity to make medical treatment decisions. Documents such as a previous adjudication of incapacity or a determination by the administrative head of the service unit that the individual has capacity may be provided.
- C. Patients With Capacity to Make Medical Treatment Decisions - If the terminally ill patient has been determined by the attending physician to have capacity to make major medical decisions, the patient shall make decisions regarding any proposed D.N.R. order or the withholding or withdrawing of life supports.
  - D. Patients Without Capacity to Make Medical Treatment Decisions - If a terminally ill patient has been determined by the attending physician to lack the capacity to make major medical decisions, decision-making in regard to medical treatment shall proceed according to the following guidelines:
  - E. For persons receiving services when BGS does not provide guardianship services:
    1. If the patient has a private guardian and is housed in a health care facility operated or funded by DDD, a DNR order may be issued with the consent of the private guardian. :
    2. If the patient is housed in a health care facility not funded by DDD, decision-making regarding the issuance of a DNR order or the withholding or withdrawing of medical treatment shall be addressed in accordance with the policies, procedures, and practices of the health care facility.
  - F. For persons receiving services when BGS provides guardianship Services:
    1. Denial of DNR - BGS may refuse consent for a DNR or the withholding or withdrawing of LSMT. This refusal may be based upon a judgement that the recommendation is not warranted by the current set of circumstances. It may also be based upon opposition to the recommendation by immediate family of the patient.
    2. Consent to DNR - If BGS agrees with a request for a DNR, a certification shall be prepared outlining compliance with the following conditions:
      - (a) A search has been made of the patient's records and no advance directive for this patient exists.

- (b) A detailed diagnosis and prognosis are provided, which substantiate a conclusion regarding the futility and negative consequences of resuscitating the patient.
- (c) The condition of the person is terminal, as defined above under Section V. A.
- (d) There is no reasonable hope of remission or cure.
- (e) A second opinion from another physician confirms the condition.
- (f) A supportive care plan is provided.
- (g) The immediate family of the patient concur with the DNR recommendation and do not know of any information that the patient would not have wished to have a DNR order entered.
- (h) Any other information deemed relevant to the determination.

If all of the conditions in the certification described above have been met, the Chief of BGS or his or her designee shall grant consent. BGS shall promptly notify P&A of the consent and provide P&A with a copy of the certification and any other requested information regarding the terminally ill patient. If P&A raises no objection to BGS's determination, the DNR order shall stand. If P&A does not agree, BGS shall withdraw the DNR consent and may seek to have a guardian ad litem appointed for the terminally ill patient.

- G. Hospice services may be provided for an individual with a terminal illness. Consideration for admission into a hospice program requires that a DNR order be in place. Consequently, all of the procedures for consent to a DNR order delineated above shall be followed prior to admission into a hospice program.

A hospice program may be provided in a health care facility specifically designed for hospice care, at a hospital, in a developmental center or in a community residence as defined in N.J.A.C. 10:44A or 10:44B. Involvement in a hospice program is the only instance where a DNR order may be considered for an individual placed in a community residence.

- H. All DNR orders shall be reviewed at least every 14 days by the attending physician, who shall document the review in the patient's record.
- I. Withholding or Withdrawing LSMT - If BGS receives a request for withholding or withdrawing LSMT, the matter shall be referred to

the Chief of BGS for review. Appropriate action shall be taken on a case by case basis.

J. Declarations of Death Based upon Neurological Criteria

1. The attending physician in a developmental center and a corroborating physician may certify that an individual is brain dead in accordance with N.J.A.C. 13:35-6A.
2. The corroborating physician shall be a neurologist or a neurosurgeon.
3. Both the attending physician and the corroborating physician shall document in the client record the results of all tests required in N.J.A.C. 13:35-6A-5.
4. A person may be pronounced brain dead if it is determined by the attending physician and confirmed independently by the corroborating physician after an appropriate period of time that brain death has occurred.
5. Neither the attending physician nor the corroborating physician shall have any interest in using the organs of the person for transplants.
6. Brain death shall not be declared if either physician has any reason to believe, based upon available medical records or from information provided by the person's family that such a declaration would violate the person's religious beliefs.
7. When all the above steps have been satisfied, the person may be removed from any life sustaining measures.
8. Both physicians shall certify the person's death in the client record.
9. The attending physician shall certify death on the death certificate.

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